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ABSTRACT

Women are a rapidly growing group of people with AIDS in the United States, and Hispanic/Latina and African American women are disproportionately represented. This paper reviews the literature on the epidemiology of AIDS/HIV infection among Latina women, children, and adolescents and discusses the needs of Latinas regarding AIDS prevention education. Approximately a half million U.S. cases of AIDS had been reported through October 1995, of which women accounted for 11 percent. Hispanics and African Americans represented 21 and 53 percent, respectively, of cases among women. Intravenous drug use by self or partner was a major risk factor, particularly in the Northeast. Children under age 13 were usually infected via maternal transmission, and Hispanic children accounted for a third of pediatric cases. Inner-city adolescents were also at increased risk for HIV infection related to high-risk sexual behaviors and drug abuse. Other risk factors for Latinas are poverty, lack of access to health care, inadequate prenatal care, culturally prescribed gender roles and attitudes, and socioeconomic and political disempowerment. Educational interventions must address the needs of Latinas within cultural context. Cultural norms may dictate that a woman appear sexually naive, making it difficult for her to negotiate safe sex practices. Development of peer support groups may be the best approach. Recommendations are offered for working with the Hispanic community. (Contains 27 references.) (SV)

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Hispanic/Latina Women and AIDS: A Critical Perspective

by Lydia Blasini-Caceres
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and
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Working Paper No. 36
October 1997

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Abstract

It is estimated that 1.5 million people in the United States are infected with HIV, the virus that causes AIDS. According to the 1996 CDC HIV/AIDS Survelliance report, the Center's for Disease Control reported 501,310 cases of AIDS in the United States as of October 1995. This number grew to 525,050 by December 1995. Fifty-one percent of the reported AIDS cases were among African-Americans and Hispanics/Latinos. These figures become more significant when compared to the national population breakdown. African-Americans represent 12.1% of the population while Hispanics/Latinos represent 9% of the population (CDC, 1995).

The Centers for Disease Control and Prevention estimate that approximately 120,000 women in United States are infected with HIV, making women the fastest growing group of people with AIDS in the United States. From this growing group of victims, African-American and Hispanic/Latino women are disproportionately represented among those with HIV/AIDS, and the disease is expected to spread at much higher rates among these groups in the coming decade (CDC HIV/AIDS Surveillance Report, 1996).

The best know prevention against AIDS at present is education, so men and women should be educated about how to protect themselves. The primary routes of transmission of HIV infection in the United States are culturally structured social behaviors, particularly the sharing of intravenous drug injection equipment and sexual acts involving the exchange of body fluids. The dangers of unprotected sex with multiple partners, anal sex, and violent sex should be explained in detail. The use of condoms and alternate forms of sexual experience should also be openly discussed. AIDS preventive education must include education about drug use as well, including the provision of clean needles or a means of cleaning them. Moreover, the government, at all levels, must also be held accountable for acceptable levels of commitment to and intervention in minority communities. This includes the provision of HIV/AIDS education programs that focus on minority issues, medical services within minority communities for those infected with the virus, and allocation of funds for research into treatment and prevention of AIDS for minorities. Additionally, we need to be sure AIDS education and services are available in minority communities, culturally sensitive, and accessible to all people.

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Hispanic/Latina Women and AIDS: A Critical Perspective

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The Julian Samora Research Institute is committed to the generation, transmission, and application of knowledge to serve the needs of Latino communities in the Midwest. To this end, it has organized a number of publication initiatives to facilitate the timely dissemination of current research and information relevant to Latinos.

- *Research Reports:* **JSRI**'s flagship publications for scholars who want a quality publication with more detail than usually allowed in mainstream journals. These are edited and reviewed in-house. Research Reports are selected for their significant contribution to the knowledge base of Latinos.
- *Working Papers:* for scholars who want to share their preliminary findings and obtain feedback from others in Latino studies. Some editing provided by **JSRI**.
- *Statistical Briefs/CIFRAS:* for the Institute's dissemination of "facts and figures" on Latino issues and conditions. Also designed to address policy questions and to highlight important topics.
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Hispanic/Latina Women and AIDS: A Critical Perspective

Introduction

Acquired Immunodeficiency Syndrome (AIDS) was first recognized in the United States, in 1981, as a disease afflicting homosexual, bisexual, and IV using males. Centers for Disease Control estimates that more than 1.5 million people in the United States are infected with HIV, the virus that causes AIDS. As of December 1995, 525,050 cases of AIDS have been diagnosed in the United States (CDC HIV/AIDS Surveillance Report, 1996). The AIDS epidemic, represents the leading cause of years of potential life lost, making it a primary public health crisis in the U.S.

Women are the fastest growing group of people with AIDS, making up 11% of all reported cases. The CDC estimate that approximately 120,000 women in the U.S. are infected with HIV. From this growing group of victims, African-American and Hispanic/Latino women are disproportionately represented among those with HIV/AIDS and the disease is expected to spread at much higher rates among these groups than others in the coming decade (CDC HIV/AIDS Surveillance Report, 1996).

At this moment, an effective vaccine or drug for the cure of AIDS has not been discovered. Education appears to be the best alternative for prevention of the disease. It is through AIDS health education that people at risk may be informed. Since women serve as the family's primary care provider, and biologically, they are the link in transmission of the Human Immunodeficiency Virus (HIV) infection to their children, women need programs that are effective, realistic and culturally sensitive. These programs should help them to: understand how they are at risk of infection; how to protect themselves and their families, and how to care for family members who are victims of AIDS.

The purpose of this paper is to review the literature concerning Hispanic/Latina women and AIDS. The paper is divided into three sections. The first section presents data and literature pertaining to the epidemiology of AIDS in Hispanics/Latinos in the United States. The second section presents facts concerning women, children, adolescents and AIDS. Section three presents the needs of Hispanics/Latinos regarding AIDS prevention. Conclusions and recommendations are stated at the end of the paper.

Epidemiology of AIDS in Latinos in the U.S.

The purpose of this section is to present data and literature pertaining to the epidemiology of AIDS in Latinos in the United States. Through October 1995, the CDC have received reports of 501,310 cases of AIDS in the U.S. This population included 170,271 (34%) cases among African-Americans, 87,387 (17.4%) among Hispanics/Latinos, 3,457 (.006%) among Asian/Pacific Islanders, and 1,283 (.002%) among Native-Americans/Alaskan Natives. These figures become more significant when compared to the national population breakdown. Fifty-one percent of reported AIDS cases were among African-Americans and Hispanics/Latinos, who represent 12.1% and 9% of the population, respectively (CDC, 1995).

The reported AIDS incidence rates per 100,000 U.S. citizens indicates that the rate of infection is six times higher for African-Americans and two times higher for Hispanics then for Caucasians. In 1995, African-Americans and Hispanics/Latinos represented the majority of cases among men (54%) and women (76%) (CDC HIV/AIDS Surveillance Report, 1996). When compared by sex and age, African-Americans and Hispanics/Latinos continue to show a higher risk of AIDS. Of women reported to have AIDS in the U.S., 53% are African-American and 21% Hispanic/Latino, making them 15 and 9 times more likely, respectively, to have AIDS than White women (National Commission to Prevent Infant Mortality, 1993). African-American and Hispanic children also reveal a higher risk based on the higher incidence of infected Hispanic and African-American women. Many children infected with the virus are infected when the virus passes from an infected mother to the fetus (CDC HIV/AIDS Surveillance Report, 1996).

The AIDS Surveillance Report shows that the largest number of males and females at risk are adults in their reproductive years. The most salient risk behaviors identified are male to male sexual contact, which accounts for the largest proportion of cases (51%) followed by use of intravenous drugs (24%). In 1995, the percentage of women in the adult/adolescent age range with AIDS was 19%, the highest proportion yet reported. Most women acquire HIV infection through drug injection (38%) or sexual contact with a man with or at risk for HIV infection

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(38%). The AIDS epidemic among heterosexual women reflects the epidemic use of intravenous drugs. As the use of intravenous drugs increases, the incidence of AIDS also increases, particularly among the heterosexual population. (CDC HIV/AIDS Surveillance Report, 1996).

Transmission of HIV/AIDS occurs through blood to blood contact or sexual contact, or from mother to infant. Although there appears to be some consensus that the AIDS virus has also been isolated in saliva, tears, and urine, the probability of infection via these body fluids is low and therefore theoretical. Breast milk continues to receive special attention due to the increase in cases of infected newborns (Hankins, 1990). Moreover, the largest increases of HIV exposure occurred among heterosexual men and women who acquired HIV through drug injection or intravenous drug use (men 11%, women 12%) or through heterosexual contact (men 38%, women 46%). Although the incidence of estimated AIDS opportunistic illness (AIDS-OIs) is increasing most rapidly among infected heterosexuals, men who have sex with men continue to represent the largest number and proportion of persons estimated to have AIDS-OIs (CDC HIV/AIDS Surveillance Report, 1995).

AIDS risks are greater for populations with higher incidences of behaviors that can transmit the virus. However, the spread of the disease is also rapid among medically underserved populations including Hispanics/Latinos and others living in poverty (New York City Department of Health AIDS Surveillance, 1989). This situation is aggravated by late or non-existent diagnoses of the disease and the failure to provide prevention information that is well disseminated and culturally appropriate.

Over this past decade, many aspects of the AIDS infection have been identified, through our experience with the disease. Most observable is the fact that the Human Immunodeficiency Virus (HIV) which causes AIDS, affects people differently. As a result, we have asymptomatic carriers, individuals with mild to severe AIDS opportunistic illness (AIDS-OIs) and individuals with full blown AIDS. Examples of AIDS-OIs include pulmonary tuberculosis, recurrent pneumonia, and invasive cervical cancer. All of these individuals (even if asymptomatic) are able to infect others. This news is most distressing for Hispanic/Latino communities in the northeastern and Midwest regions of the United States where more than half of the cases of AIDS among African-Americans and Hispanics/Latinos are associated with IV drug abuse by heterosexuals (Singer, Flores, Davison, Bunker, and Castillo, 1991). According to the SEICUS Report (1990), the changing composition of groups most at risk for contracting AIDS will have a devastating effect on the Hispanic/Latino community. There is also a rapid increase in the number of cases among females of childbearing age, children, and adolescents. It is no longer a White male disease.

Women, Children, Adolescents, and AIDS

This section will present facts regarding women, children, adolescents, and AIDS. Women comprise a steadily growing group of people with AIDS. African-American and Hispanic/Latino women make up 21% of all women in the United States, but more than three-fourths (77%) of AIDS cases reported among women in 1994 occurred among African-American and Hispanics/Latinas. For adult and adolescent women (those 13 years and older), the AIDS case rate per 100,000 individuals in the U.S. population in 1994 was 3.8% for non-Hispanic Whites; 62.7% for African-American; 26.0% for Hispanics/Latinos; 1.3% for Asian/Pacific Islanders, and 5.8 for American Indian/Alaskan Natives (CDC National AIDS Clearinghouse, 1995). This finding takes a serious significance when we consider that maternal transmission of AIDS to newborns has been well demonstrated (Brooks-Gun, Boyar, and Hein, 1988).

Children (under 13 years old) are currently one of the fastest growing AIDS populations (Heywood and Curran, 1988). As of November 1988, 82% of pediatric AIDS cases in New York state were reportedly infected via maternal transmission and only 4% were infected via blood or blood products. Of pediatric AIDS cases, 89% had onset of the illness by age four. The disproportionate distribution of AIDS among racial groups is also evident in the pediatric population; Whites account for 11%, African-Americans for 56%, and Hispanics/Latinos for 33% of cases (AIDS in New York State, 1988). The high level of HIV drug abusers in the northeast is believed to have a significant influence on the disproportionate percentage of AIDS among African-Americans and Hispanics/Latinos. In addition, there have been increases in the number of adolescent AIDS cases reported in the South and Midwest, with rates three to six times higher for the African-American and Hispanic/Latino populations (CDC, 1991).

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Researchers at the CDC have produced some shocking data regarding the risk of AIDS among Puerto Ricans in the United States. They looked at Latin American born persons in different regions of the United States and found that the cumulative incidence of AIDS in heterosexual intravenous drug abusers (IVDAs) in Puerto Rican born persons was several times higher in every region than for other Latin American born persons. Researchers state these findings were most appreciable in the northeastern United States where almost three fourths of Puerto Ricans by birth or ancestry reside. Their geographic concentration in areas of high intravenous drug abuse partially explain these findings (Selik, et. al. 1989).

Another group which is now recognized as being at increased risk of AIDS and in need of immediate effective intervention is adolescents, particularly inner-city adolescents. Inner-city adolescents are at increase risk for HIV infection because of their high-risk behaviors (Berger, Rivera, Perez, and Firman, 1993). There are many factors which contribute to adolescents' risk level. Among them are poverty, homelessness, and elevated high school dropout rates. Without skills or an education, they soon find themselves with limited options (Hein, 1987). The most common risk factor among adolescents is sexual risk taking behavior, including having STDs (a risk factor associated with HIVinfection), limited use of contraception, having been sexually active for a long period of time, and multiple sex partners (Berger et al, 1993). In addition, teenagers become sexually active early; the average age can be as early as 12 years old, in some regions, though the national average is 16 years old. In 1987, 10% of the babies born with AIDS in New York City were born to women younger than 21 years old. Most of these mothers were asymptomatic to AIDS at that time (Brooks-Gunn, Boyer, and Hein, 1988).

Crack (a smokable form of cocaine) has found quick acceptance, especially among our adolescent population. It is easy to obtain, easy to use, inexpensive, and enables the user to reach the desired high quickly. It is very addictive and often causes the user to engage in sexual hyperactivity (Joseph, 1989). Once under the influence of the drug, they are unable to use judgment regarding safe sex practices. In addition, addicted individuals will often trade sex to support their habit adding to the risk factors for contracting the HIV virus (Kerr, 1989). In his 1993 article entitled "Risk Management for HIV Among Pregnant Adolescents" D. K. Berger and his associates state that "Crack cocaine, although not a risk factor for adults, may be one for adolescents" (p. 601). When we consider these features of crack addiction, its potential for spreading AIDS becomes obvious.

Adolescents may use sex as a means of supporting a drug habit or they may become involved with individuals older than they are. These adults are individuals who have had numerous sexual partners and therefore are at higher risk of infection (Hein, 1988). This is truly a frightening finding in light of the resurgence of sexually transmitted diseases in the United States. Bolling, and Voeller (1987) believe that the skin lesions which result from diseases such as syphilis and herpes leave the individual more susceptible to getting or transmitting the HIV infection. The cases of sexually transmitted diseases are increasing in cities with large poor populations-areas whose resources are already stretched thin (Kerr, 1989).

There are several other factors that place Hispanics/Latinos at higher risk for HIV infection. These include: poverty, lack of access to healthcare, late or inadequate prenatal healthcare, culturally prescribed gender roles, and gender attitudes, and socioeconomic and political disempowerment (Maldonado, 1991). All of these factors mitigate heavily against the healthy growth and development of young Latino women. In addition, religious and cultural beliefs tend on the one hand to serve to protect but on the other hand keep them at risk. Therefore, their level of acculturation and socialization, like their educational and socioeconomic level, must be recognized when determining their risks and needs.

Many Hispanic/Latino women are at high risk for infection because of culturally prescribed gender roles. In the Hispanic/Latino community, sexual matters are viewed as private and personal, and discussions of these matters are considered taboo. Many Hispanic/Latino women have little understanding of sexuality and little understanding about their bodies' sexual responses. Sex is viewed in the context of procreation and giving pleasure to their sexual partner. Further complicating the issue are the traditional views of Hispanic/Latino women. Cultural standards dictate that they have little knowledge about sexuality, or about the use of condoms. Hispanic/Latino men on the other hand are expected to have a great deal of sexual knowledge and to begin sexual contact at an early age (Marin, 1990). Intervention is most desirable in

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this segment of the population if we are to see changes in health statistics. However, these interventions must take into account the cultural parameters of the population and incorporate techniques that both address and respects the cultural needs of this population.

Meeting the Needs of Latinos

This section discusses the needs of Latinos regarding AIDS prevention. Acknowledging the presence of AIDS in the community means recognizing the existence of homosexuality, bisexuality, IV drug abuse, and extramarital affairs. Making these acknowledgments requires confronting some of the cultural taboos and gender role expectations which are part of the culture's very matrix (Scott, Shifman, Orr, Owen, and Fawcett, 1988).

Just providing AIDS prevention information is too simplistic an answer if it fails to recognize the cultural context within which women must make decisions. Hispanics/Latinas come from societies with strong patriarchal family structures, strict cultural norms, and strong church influence (Amaro, 1988). This patriarchal influence controls every aspect of a woman's life including: manner of dress, social activities, interpersonal relationships, courtship, marriage, and child bearing. It also allows for a double standard in regard to male promiscuity. These cultural dynamics have contributed to Hispanic/Latinos' vulnerability to the AIDS epidemic.

The use of condoms has been promoted as one of the cornerstones to preventing the spread of HIV/AIDS. However, it is no simple matter for Hispanics/Latinos to negotiate for safer sex practices. Cultural norms dictate that women appear naive about sexual matters; a woman prepared for sexual encounters is considered a licentious woman (Worth and Rodriguez, 1987). If married or in a monogamous relationship they may consider themselves not to be at risk. Asking for safe sex practices or asking about previous partners or drug abuse could jeopardize their relationship. They fear they will alienate someone who can provide support, companionship, and protection. Because of their lack of marketable skills and the poverty within which these women live, they believe that having someone is better than being on their own.

Another recommended action to help prevent the spread of HIV infection is for HIV+ women to postpone pregnancy or to abort if already pregnant. Neither one of these options may be possible for some Hispanics/Latinas. This may be due to cultural, religious or socioeconomic reasons. Asking these women to postpone motherhood negates the role that being a mother plays in their life. It may be the one time they feel special and worthwhile (Mitchell, 1988). They feel, that by aborting their pregnancies, they are being asked to kill their child now because it may die later. Even though the probability of bearing an infected child can be as high as 60%, these women often feel some chance of having a child is better than no chance at all. It is part of them and part of how they define themselves and their womanhood. In addition to the religious beliefs which rule against abortion is the fact that many of these women do not seek prenatal care until it is unsafe for them to have an abortion (Mays and Cochran, 1988). For IV using women the problem is even more complicated. Among them there is a high rate of pregnancy, but little utilization of available prenatal care. There are several factors that contribute to the high pregnancy rate among Hispanic/Latina women. The lack of resources available in Hispanic communities and strong religious beliefs prevent women from obtaining proper birth control or information. In addition, women who use drugs tend to miss periods, which lead to false assumptions that pregnancy cannot occur (Hoffman, 1990).

Selik, Castro, and Pappaioanou (1988) indicate that the proportion of women with AIDS, who are IV drug users or whose male partner is an IV drug user, is substantially higher among Hispanics/Latinas (80%) than among Anglo (52%) women. The rates of intravenous drug-related HIV transmission make this mode of transmission a vital part of prevention education. Drug addiction will affect a woman's ability to practice safe sex behaviors, her ability to parent, and her ability to negotiate for safe drug paraphernalia. It is not a behavior that is carried out in isolation but a behavior that makes the individual part of a subculture (Mays and Cochran, 1988). For the woman who lacks non-drug related support systems, the drug using community becomes her family. It is not easy for her to change her behavior — even under the threat of death.

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Attitudes related to homosexuality and bisexuality also need to be addressed. Because of cultural taboos and religious doctrine, the Hispanic/Latina parent of a homosexual or wife of a bisexual can find herself completely isolated. Without the support of family and friends she may be left alone to face fear and loneliness as she contemplates her own risks or cares for a loved one dying from disease.

Conclusions and Recommendations

Slowing the spread of AIDS in populations that are most at risk must go beyond merely allocating funds. In some cases the structure of the organizations that disburse and offer services is a barrier; in other cases, it is the interplay between members of minority cultures that is the barrier. Goicoechea-Balbona (1994) state that both of these factors affect the delivery of educational and social services to Hispanics/Latinos, a population at high risk for contracting HIV/AIDS.

Educational interventions must address the needs of Hispanic/Latina women within cultural context. It is not enough to provide bilingual information. Materials and techniques must demonstrate a sensitivity to cultural norms. There is a need for culturally sensitive educational programs that will help women understand their risks.

These programs must focus on making AIDS prevention a shared responsibility between men and women rather than a woman's responsibility to protect herself. Men need to be equally targeted for behavior change. For the Latino/Hispanic community it is important to develop strategies for prevention that focus on the specific needs of both the male and the female. Due to the barriers within the community, regarding sexual practices, intervention would best take place separately for men and women. For Latino/Hispanic men, prevention programs need to take into account their sense of machismo. The whole concept of machismo can be used in a positive context, by drawing attention to their role as protectors of their family which may be a stronger motivation of behavior change than fear of their own risk. Establishment of focus groups for men may enable a facilitator to discuss safe sexual practices in terms that allow the participants to feel comfortable and receptive. Focusing on the males responsibility to protect his partner and children will allow greater discussion of the need to incorporate safe sexual practices into a healthy lifestyle.

For women, the best approach may be the development of peer support groups. These groups should take place in neutral locations that make the women feel safe in discussing sexual issues. Groups may take place within the home or a community agency that the women are familiar with. The groups should focus on the dissemination of information, but should not dissuade women who are uncomfortable with carrying out suggestions. The facilitator should remember the cultural barriers that many of these women face in terms of their own sexuality. The provision of information and the development of a format to discuss sexual issues is a good foundation in the building of a program to prevent the spread of HIV within this population. As the women become more comfortable, it may be possible to introduce further prevention techniques.

For both Latino/Hispanic men and women, it is crucial to incorporate family and peers as part of any prevention strategy. The family and peer unit is a vital part of the lifestyle of this group. Any intervention needs to focus on the role the persons assume within the family. This family role may persuade those at risk to use precautions as a means of carrying out family responsibilities.

There are other considerations that need to be taken into account when working with the Latino/Hispanic population. Health educators need to begin with themselves and be clear on what value judgments they may have about the people they are working with. Only then can they hope to give culturally acceptable verbal and non-verbal messages. The development of trust is essential to a program's success. The health educator in this environment should be well aware of cultural barriers and able to design programs that take into account the needs of this population.

In addition to the above suggestions, there are several other recommendations that can be utilized when working with the Latino/Hispanic community.

1. Conferences are a useful strategy that allow the dissemination of information about health related topics. Conferences permit the presenters to be more close to the audience, and to present the information face to face. Hispanics in general like this approach better and the information is better received when body language and gestures are used. Also, conferences allow the presenter to get into the community in a unique way.

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2. Festivals provide the opportunity to involve a large percentage of the community, and make people more relaxed and willing to receive the information. Hispanics enjoy the auditory and visual aspects of festivals more than reading. Festivals are a means of reaching large groups of individuals with a specific message.

3. There should be increased focus on the design and implementation of in-service training for health service providers. Training should include strategies for the development of culturally sensitive programs and materials.

4. It is essential to establish more networking between Hispanics, health service providers, and government agencies. This includes the hiring of more bilingual staff within these agencies.

5. More advertising regarding educational information, services, and programs by using the media-television, radio, newspaper, and posters around public places, stores, and restaurants.

6. The use of support groups led by role models that participants can identify with should be encouraged. Support groups and self-help models could be promoted to help women deal with their own illness as well as that of their loved ones. Support groups could also be used to explore concerns around all aspects of the AIDS epidemic and what it signifies for the Latino community.

The government must also be held accountable for acceptable levels of commitment to and intervention in minority communities. On state and local levels, we need to be sure that culturally sensitive AIDS education and services are available, and accessible to all people. There also needs to be increased allocation of funding to provide better treatment and prevention services. Finally, there needs to be increased commitment among Latino/Hispanic agencies to provide assistance to those community members most at risk for contracting this virus. Only with the help of the community itself can prevention programs even begin to stop the spread of this deadly virus.

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